



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH
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October 4, 2002

TO: Washington State Board of Health Members

FROM: Linda Lake

RE: GENETICS TASK FORCE REPORT

Summary and Background

As Chair of the Genetics Task Force (GTF), I submit the attached report titled "Genetic Privacy, Discrimination, and Research in Washington State: Findings, Conclusions, and Recommendations of the Washington State Board of Health Genetics Task Force."

The Board established the GTF in response to a proviso in the state's biennial budget-Engrossed Substitute Senate Bill (ESSB) 6153, Section 220.8. As directed by the legislature we convened a very diverse group including, some of our state's and nation's top genetics scientists, representatives from ACLU, the business community, the bio-tech. industry, the ethics community, and citizens affected by developments in genetics. The GTF comprised 22 members in all. A full roster of GTF members is included in the report.

The GTF met five times for full day meetings each time, over a nine-month period, according to the Work Plan approved by the Board in October 2001. During those meetings, the GTF considered an extensive volume of information from genetics experts, state agency personnel, legal experts, and its own very capable staff. During its deliberative phase, the GTF formed four sub-committees from its own membership. These sub-committees considered in detail the information the larger group had heard. These sub-committees developed issue statements with conclusions and recommendations that formed the basis for the bulk of the final report. Finally, a draft of the report was circulated for public comment via the Board's website. At its September 4 meeting, the GTF heard several comments from the public about the report. Based on this input, and their own views, the full GTF debated and modified some of the report's conclusions and recommendations during this final meeting. Subsequent to that, each GTF member was asked to submit detailed comments and their position on the report via email. .

The attached report is the result of that process. It summarizes the complex issues surrounding privacy, discrimination, and research in the context of emerging DNA technologies. I am proud to report that the GTF achieved agreement on the vast majority of the recommendations presented here. However, there were a few areas in which several GTF members were not able to come to consensus. In these areas, the report indicates the points of disagreement, the members who disagreed and the thought processes by which they diverged from the majority

view. While I would have preferred unanimity on all points, I am pleased the GTF was able to reach agreement on so many of these challenging topics. The lack of agreement on some issues clearly illustrates their complexity, and provides valuable insight on the positions on each side. In the end, no fewer than nineteen of the GTF's 22 members endorsed the report. I feel that this is an indication that the report represents an accurate and comprehensive overview of the GTF's process, findings, conclusions and recommendations.

The report contains a wide range of background on current issues in genetics, on privacy and discrimination laws in this and other states and on the effects of those laws. The report contains several recommendations to improve privacy and circumstances surrounding the possibility of discrimination based on genetic information. The following recommendations, made both to the Board and to the Legislature are perhaps the most salient:

1. Support and authorize funding where necessary for efforts to educate consumers, research subjects, researchers, health care providers, employers, and insurers about how genetic information derived from genetic testing, as part of medical information, can be used, the concepts and consequences of anonymity in research, and the reporting and other mechanisms available to those who believe they have been discriminated against. These efforts should include: 1) providing information to consumers, research subjects, researchers, health care providers, employers, and insurers about existing laws and penalties for violations regarding the privacy and appropriate use of genetic information; 2) establishing a graduate program in genetic counseling at the University of Washington to address the current and future needs of the state's population.
2. Change Chapter 49.60 RCW to explicitly include "genetic information" in the list of characteristics that receive protection under the law. The GTF recommends that "genetic information" be defined as "Information about inherited characteristics. Genetic information can be derived from a DNA-based or other laboratory test, family history, or medical examination."
3. Adopt in rule the existing administrative policies protecting the privacy of newborn screening specimens and other tissue samples held by the state.
4. Create policy to make all research in the State of Washington involving genetic information obtained from human subjects subject to the standards that are in place for federally funded and/or regulated human subjects research.

Recommended Board Action:

The Board accepts the final report of the Genetics Task Force and forwards it to the Legislature according to the terms set forth by the legislature in the budget language creating the Genetics Task Force.